# **International Journal of Social Science and Human Research**

ISSN (print): 2644-0679, ISSN (online): 2644-0695

Volume 07 Issue 05 May 2024

DOI: 10.47191/ijsshr/v7-i05-38, Impact factor- 7.876

Page No: 2833-2843

# Caregiver Burden for Carers of Chronically Mentally Ill Patients: A Study With Families in Cyprus

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ABSTRACT: Having a chronically mentally ill person in the family presents a challenge for the entire family system, not only on a daily life basis but also regarding their psycho-emotional and social life. The present study focuses on caregivers of chronically ill patients' burden on four levels of possible disruption: the economic burden, the impact on family life, sociability, health, and behavior, and the impact of perceived aggression by considering the demographic characteristics of the caregivers, but also the socio-demographic characteristics of the chronically ill family member(s) they are taking care of. We conducted a quantitative survey with a sample of 90 family members/caregivers and the corresponding 90 chronically ill patients under their care from all districts of the Republic of Cyprus. Participants completed the "Family Burden Scale" (FBS-23) (Madianos et al., 2004), a personal information form with demographic information, and a questionnaire regarding the demographics and the illness trajectory of the chronically mentally ill family member (age of disease onset, diagnosis, frequency of episodes). Our findings showed that most caregivers providing systematic care for a family member experienced high levels of disruption in their daily routine and sociability, perceived high levels of aggressive behaviors, felt moderately affected in their health and behavior, and carried a heavy economic burden. Older participants felt a significantly higher economic burden than younger caregivers, who perceived a significantly more significant negative impact on their health and behavior from taking care of a chronically ill family member.

KEYWORDS: caregiver burden, chronic mental illness, economic burden, mental health, stress.

#### 1. INTRODUCTION

# 1.1. Mental illness in the family

Mental illness not only has adverse and disruptive consequences for the person who suffers, but at the same time, family members also experience the consequences of the disease. Worldwide, mental illness affects at least one member of every eight families (WHO, 2022). A clinically significant disruption in an individual's behavior, emotion regulation, or thought processes indicates a mental disease. Usually, it is linked to distress or impairment in critical domains of functioning.

Historically, the deinstitutionalization of the mentally ill began in the mid-1980s, after which most patients went back to live with family members. Along with this residential shift, mental health practitioners and society at large started to place responsibility for the development of mental disorders on families. Since the mid-1980s, there has been another phase in which families and experts have worked together to mitigate the effects of mental illness on the family. According to this viewpoint, a family member's illness is not attributed to the family; instead, Rende and Plomin (1993) consider it to result from a confluence of environmental and hereditary elements.

Findings by <u>WHO</u> (2022) indicate that having a family member with a mental illness can be very disturbing and even dangerous. Such a revelation in the family significantly affects the whole family system and all aspects of their social and psychoemotional life. Mental disorders may become more complex due to cognitive or intellectual impairment, societal difficulties, or coexisting medical conditions (<u>Wade & Halligan, 2017</u>). Individuals suffering from severe mental illnesses, such as psychotic disorders, personality disorders, and substance abuse, are severely disadvantaged. Patients often describe upsetting and unpleasant experiences throughout therapy (<u>Selwyn et al., 2021</u>) and may experience a range of emotions, including anxiety and – even - hope (<u>Papathanassoglou, 2010</u>). Chronically mentally ill patients may rely on friends, family, and coworkers for practical and emotional support, while the nature of the ailment and its accompanying disadvantages may limit accessible resources.

Intense and frequently rapidly changing emotions are common in people with mental illness, which they may find difficult to control. These problems may worsen due to the illness's physiological alterations and medications. Early research by family

scholars and clinicians who worked closely with families with severe mental disorders greatly influenced the first studies of family stress and coping strategies related to mental illness (Nichols & Schwarz, 1991). It is usual for (family) carers to feel strongly about another person's emotional display, especially if it appears inappropriate. The idea of a subjective burden—a family member's assessment of the sickness and the experience of caring—is a crucial issue in this study. One significant subjective burden, for example, that many families with mentally ill family members experience is the stigma associated with mental illness, both within the family and in society at large (Schock & Gavazzi, 2005). When working with people with mood disorders, common reactions include frustration, anger, hopelessness, anxiety, and fear.

At the beginning of the new millennium, growing research on the caregiver burden, poor caregiver results, inadequate caregiver support, and inconsistent achievements with interventions aimed at decreasing the caregiving burden reflected the growing recognition of the role of caregivers in the long-term management of psychiatric patients. What is more, patients with an integrated caregiver-centered perspective have been the focus of psychiatric rehabilitation (Burton et al., 2003).

#### 1.2. Caregiver "burden"

The term "family caregiver" refers to a person who provides care for another person who is dependent on them. Although there is no precise definition of "family caregiver," it is generally accepted that this term includes providing care beyond the ordinary in family relationships.

Typically, providing care involves investing time, energy, and money over long periods. It involves tasks that can be unpleasant, difficult, tiring, psychologically stressful, or physically exhausting (<u>Schulz & Martire, 2004</u>). Often, a family member of a person with mental health problems takes on the role of carer, a heavy responsibility with stressful outcomes. Inextricably linked to the term "caregiver" is the concept of "burden." The literature refers to caregiving stress as a caregiver burden. <u>Treudley</u> (1946) was the first to propose the idea, citing the harmful effects of caregiving on the caregivers' mental health and quality of life. The problem of caregiver burden is multidimensional and, according to <u>Statharou et al.</u> (2011), not only depends on the characteristics and problems of the patient but also extends within the broader theoretical framework of stress and coping. Caregiver burden is a universal worldwide phenomenon (<u>Magliano et al., 2005</u>).

Early on, the caregiver burden was divided into objective and subjective dimensions, and the factors that may affect it vary according to the type of illness, the relationship with the patient, the length of time of care, the carer's age, and other factors (Platt, 1985). Hoeing and Hamilton (1966) were the first researchers to distinguish between the objective and subjective dimensions of the emotional load. The objective burden is the number of activities the caregiver performs and the time pressures of providing support for these tasks, whereas the subjective burden is the emotional or psychological toll that caring responsibilities have on caregivers (Tough et al., 2019; Tough et al., 2017).

The literature reports that families providing care are at risk because they lack specific knowledge about care and accessing information and professional support. This disadvantage is frequently brought about by the stigma and lack of knowledge around mental illness among the typical sources of support, such as friends, coworkers, and extended family. Even in cases where families take on the care of their relatives on their initiative, and even if they do so with pleasure, the consequences of continued supervision cause adverse effects on the health, family relationships, and future financial security of family members.

The purpose of the current research is to examine the effects of burn-out on the family carers of chronic mental illness patients during the development and course of the illness. We posed the **following research questions:** 

R1: To what extent and by what factors are family members of the chronically mentally primarily ill burdened?

R2: How do caregivers' demographic characteristics affect their perceived burden from caring for a chronically ill family member?

#### 2. METHODOLOGY

This study aimed to research the effects of caregiver burden on carers of chronically mentally ill patients. We chose a quantitative methodology to detect relationships between various factors related to the caregiver burden phenomenon. The quantitative measurement of family burden involves assessing the factors that affect the family's daily life. The quantitative approach provides concrete data on the degree and frequency of the burden on families due to the care of the mentally ill.

#### 2.1. Data collection process

We approached and selected the sample of 90 family members, "caregivers" of chronically mentally ill people through the mental health professionals working in the Vocational Rehabilitation Units and Outpatient Clinics of the Cyprus National Health System. That is, mental health professionals put the researcher in contact with the families of individuals receiving treatment from mental health services. One of the parents or other family members who mainly was burdened with caring for the mentally ill person was asked to respond to (a) the Family Burden Questionnaire created by Madianos and Economou in 1993 and revised in 2004 (b) a Personal Information Questionnaire and (c) the Questionnaire on the Condition of the Mentally Ill Family Member. Researchers asked the participating caregivers (family members) to record the demographics and socio-demographic data of the

patients under their care, including three questions regarding their diagnosis and the development of their mental health condition over time.

The questionnaires were given in hard copy to participants through the mental health professionals. We informed all participants that the information would be confidential and used solely for scientific purposes. The questionnaires were structured to be easy and quick to complete, and participants could answer all questions by ticking the box of their choice.

The data collection process occurred from July 7<sup>th</sup> to November 15<sup>th</sup>, 2021. We obtained permission to collect data from the Cyprus National Bioethical Committee, the Cyprus Mental Health Services, and the Office of Research and Innovation of the National Health Services Organization.

#### 2.2. Sample

The sample of the survey consisted of a family member in the role of caregiver in families with at least one patient with chronic mental illness.

Table 1: Demographic characteristics of the 'caregivers'

Demographic characteristics of care	egivers		
Variables	Characteristics	N=30	%
Gender	Men	24	27
	Women	66	73
Age	18-40 years	22	24.4
	41-63 years	46	51.2
	64+ years	22	24.4
Family status	Married	54	60
	Not married	36	40
Educational level	Primary education	14	16
	Secondary education	38	42
	Tertiary education	38	42
Place of residence	Urban area	62	69
	Rural area	38	31
Degree of family relation	Parent	34	38
	Sibling	18	20
	Offspring	20	22
	Friend/or distant relative	14	16
	Spouse	4	4

The sample of "Caregivers" consisted of 90 people, of which 66 were women (73%) and 24 (27%) were men. When we collected the data, most participating caregivers were between 41 and 63 years old, and 60% were married. Regarding their level of education, 42% had completed secondary and tertiary education. As to their residence, the most significant proportion of caregivers resided in urban areas (69%). Finally, concerning the degree of kinship of the caregivers, the majority were parents (38%), followed by the patients' offspring (22%), siblings (20%), friends/relatives (16%), and a spouse (4%) (Table 1).

#### 2.3. Instruments

#### 2.3.1. The Family Burden Questionnaire

To assess the family burden, precisely the caregiver burden, we applied the Family Burden Questionnaire created by <u>Madianos and Economou</u> in 1993 and revised in 2004 in Greek. The questionnaire aims to record the degree of subjective and objective burden that accompanies the care of a mental illness patient with severe symptoms in the six months preceding the completion of the scale. It includes 22 questions, which correspond to the following four subscales: (1) Impact on everyday life and social relations, (2) aggressive behavior, (3) effects on health and behavior, and (4) economic burden. Every question has a three-point rating system, where a value of "0" denotes no burden and a value of "2" represents a heavy burden. Higher overall and component ratings indicate a more significant burden. According to <u>Madianos et al. (2004)</u> and <u>Economou et al. (2014)</u>, the scale and its four subscales showed strong internal consistency and solid psychometric qualities (Cronbach's range: a=0.83-0.86).

# 2.3.2. Personal Information Form(s)

The researchers asked the participating caregivers (family members) to record their socio-demographic data (gender, age, educational level, marital status, place of residence, and relationship to the patient) as well as the socio-demographic data of the patients under their care (gender, age, educational level, marital status, place of residence, employment, age of onset of psychotic episode, frequency of psychotic episode and medical diagnosis).

#### 2.4. Data analyses

We used Excel to clean, code, and score all the data from the Family Burden Questionnaire and the Personal Information Forms and applied SPSS (25.0) for the data analysis. Confidence intervals are reported at 95%. We applied descriptive statistics such as standard deviation, mean, frequency, and percentages to describe the characteristics of the sample. We set the p-value (significance level) at p< 0.05 to examine the statistically significant differences. Also, to investigate the study's research questions, we conducted statistical analyses such as Analysis of Variance (ANOVA) to detect statistically significant differences in the 22 statements about the caregivers' age, education level, and employment history. We used the t-test means comparison to compare the means of the subjects' demographics (gender, nationality, urban/rural area of practice, and specialization). A Kaiser-Meyer-Olkin (KMO) and Bartlett's Test also examined whether our sample data was adequate for exploratory factor analysis. The KMO test for the "Family Burden Questionnaire" generated a score of 0.725. After the content analysis of the statements loaded to the factor derived from the factor analysis (factors with an eigenvalue >1), we conducted new variables and estimated their means for further analyses.

#### 3. RESULTS

#### 3.1. Descriptive Statistics of the Family Burden Questionnaire

The results of the Kaiser-Meyer-Olkin (KMO) sampling adequacy measure and Bartlett's test of sphericity showed a KMO index of 0.75, indicating a relatively high level of sampling adequacy. Bartlett's test of sphericity, with an approximate chi-square value of 1201.4 and 231 degrees of freedom, tested the hypothesis that the correlation matrix is an identity matrix necessary for factor analysis. The obtained p-value = 0 indicated that the variables in the correlation table were significantly correlated, indicating that the data was suitable for factor analysis. Using the Principal Component Analysis (PCA) method, we extracted the eigenvalues, percentage of variance, and cumulative percentages for each principal component.

Table 2: Factor loadings of the items of the "Family Burden Questionnaire"

Rotated Component Matrix<sup>a</sup>

	Component						
	1	2	3	4			
Q12	.831						
Q11	.797						
Q10	.760						
Q6	.756						
<b>Q</b> 9	.747						
Q7	.738						
Q8	.701						
Q17		.673					
Q22		.646					
Q18		.612					
Q19		.581					
Q21		.577					
Q20		.563					
Q3			.812				
Q1			.679				
Q4			.656				
Q2			.527				
Q5			.495				
Q14				.766			
Q16				.733			
Q13				.707			
Q15				.675			

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 9 iterations.

The application of the Varimax rotation method for the Family Burden of Caregivers of Chronically Mentally Ill Caregivers questionnaire showed that the loadings of the 22 statements were all high (above 0.500), which allowed for the adoption of the original model of Madianos & Economou (2004). The content analysis showed that for the first factor, the components expressed the dimension of "Economic burden"; for the second factor, the components showed the elements of "Impact on daily life and social life," while the third factor expressed "Aggressive behavior," and for the fourth factor "Impact on health and behavior."

Table 3: Internal Consistency and Reliability of the Family Burden Questionnaire

	Instrument	Cronbach's alpha
	Questionnaire Family Burden	.869
Factors	Economic Burden	.753
	Impact on daily life and social life	.757
	Aggressive Behavior	.757
	Impact on health and behavior	.885

Table 3 presents the Family Burden Questionnaire's internal consistency and reliability measures and that of its four factors, which are considered very high. The overall score of the Family Burden questionnaire was  $\alpha$ =.869; the economic burden factor was  $\alpha$ =.753; the impact on daily life factor was  $\alpha$ =.757; the aggressive behavior factor was  $\alpha$ =.757, and the impact on health and behavior factor was  $\alpha$ =.885 (Table 4).

Research Question 1: To what extent and by what factors are family members of the chronically mentally primarily ill burdened?

Table 4: Caregivers' perception of family burden on the four factors of the Family Burden Questionnaire

Factors of Family Burden	Low	Medium	High		
Impact on daily & and social life	22.2% (N20)	35.6% (N32)	42.2% (N38)		
Aggressive Behavior	13,3% (N12)	31,1% (N28)	55,6% (N50)		
Impact on health and behavior	37,8% (N34)	40,0% (N36)	22,2% (N20)		
Economic Burden	0,00% (N00)	44,4% (N40)	55.6% (N50)		

Table 4 illustrates the caregivers' answers to the four factors of the Family Burden Questionnaire. For the first factor, i.e., the impact on daily activities and social life of caring for the chronically mentally ill, the majority of the family members (42.2%) reported a high burden, implying that there are significant variations in daily schedule, house cleaning, a significant reduction in leisure time (with a reduction in enjoyable activities) and a significant reduction in social life. The proportion of carers experiencing similar issues to a moderate degree was over a third of the sample (35.6%). In comparison, 22.2% of carers appeared to feel the family burden only to a low degree. More than half of the caregivers (55,6%) reported aggressive behaviors to a high degree (second factor). However, they perceived aggressive actions more so at the level of family conflicts with the patient, general upset in the family and the home, and less so in severe damage inside or outside the home by the patient's actions. One-third of caregivers considered aggressive behavior moderate, while 13.3% of family caregivers experienced aggressive behavior only to a low degree. The third factor related to caregivers' assessment of the impact on health and behavior in the family when the patient remained at home, cared for by a family member. This factor relates to the manifestation of anxiety, nervousness and increasing worry, general fatigue, sleep disturbances, symptoms of melancholy, and inability to carry out daily activities both in the caregiver and other family members. Most caregivers considered themselves moderately affected (40%), while 37% to a low degree, and only 22.2% of caregivers experienced adverse effects on health and behavior either of themselves or another family member. Finally, as for the fourth factor, the financial burden that the affected person's family carried on their shoulders, more than half of the caregivers surveyed, 55.6%, said they felt a high, and 44%, a moderate economic burden. Indicative of this factor is that no caregiver reported experiencing the financial burden to a low degree. The fact that the patient either stops working entirely or, for reasons related to the diagnosis, earns less than before, or that a family member stops working to devote themselves to caring for the sick person. In contrast, another family member maximizes working hours to cover family living costs, which lays a significant financial burden on the entire family.

# 3.2. Relation between the demographic characteristics of caregivers and factors of the Family Burden Questionnaire

**Research Question 2**: To what extent do caregivers' demographic characteristics impact the degree of burden they experience?

Table 5: Caregivers' Gender and Family Status and Factors of the Family Burden Questionnaire

	Caregivers dem	ographic	es .			
Factors of the Family Burden						
Questionnaire	Gender		N	Mean	F	Sig.
Aggressive Behavior	Male	24		6.1667	15.004	0.05*
	Female	66				
Impact on Health and Behavior	Family Status					
	Single	36		4.8889	5.005	0.03*
	Married	54				

The table above (5) shows a statistically significant difference between the caregiver's gender and the dependent variable aggressive behavior F(1, 88) = 15.004, p < 0.05. Male caregivers reported that the chronically mentally ill patients they cared for exhibited more aggressive behaviors than did female caregivers. Moreover, a statistically significant difference exists between the caregivers' marital status and the dependent variable aggressive behavior F(2, 87) = 5.005, p < 0.034]. Married caregivers perceived that the family members they cared for with chronic mental illness displayed more aggressive behaviors compared to single caregivers.

Table 6: Caregivers' Age, Educational level, Degree of family relationship, and Factors of the Family Burden Questionnaire

Caregivers' demogra	pnics					
Age Factors of the Questionnaire	Family Burder	n Sum of Squares	df	Mean Square	F	Sig.
Economic Burden	Between Groups	22.103	2	11.052	3.325	.041
	Within Groups	289.186	87	3.324		
	Total	311.289	89			
Impact on Health	Between Groups	75.932	2	37.966	2.852	.053
and Behavior	Within Groups	1158.024	87	13.311		
	Total	1233.956	89			
Educational Level						
		Sum of Squares	df	Mean Square	F	Sig.
Impact on daily and	Between Groups	63.495	2	31.747	2.488	.050
social life	Within Groups	1110.105	87	12.760		
	Total	1173.600	89			
Caregivers' relation t	o the mentally ill f	amily member				
		Sum of Squares	df	Mean Square	F	Sig.
Impact on health and	Between Groups	165.736	4	41.434	3.297	.015
behavior	Within Groups	1068.219	85	12.567		
	Total	1233.956	89			

Table 6 illustrates the statistically significant difference between caregiver age, and the dependent variables: (a) Economic burden F (2,87) = 3.325, p<0.041. Older caregivers felt to a greater extent than the younger ones that taking care of a chronically mentally ill family member constituted an economic burden. (b) Health and behavior F(2, 87) = 2.852, p<0.053. Younger caregivers felt that their health and behavior were negatively impacted more than those older.

Our findings also indicated a statistically significant difference regarding the educational level of the participating caregivers in the way that they assessed the impact of caregiving on their daily routines and social life F(2, 87) = 2.488, p < 0.050]. Caregivers with a higher educational level felt a more significant impact on daily and social life than younger caregivers.

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Additionally, our findings show a statistically significant difference between the caregivers' degree of family relation to the patient and the dependent variable health and behavioral impact F(4, 85) = 3.297, p < 0.015]. We observed that sibling caregivers perceived that family members with chronic mental illness mental illness had a more negative impact on their health and behavior than the other related caregivers.

#### 4. DISCUSSION

The emphasis on mental health care has changed over the last 25 years from institutionalization to community-based initiatives and brief hospital stays. This shift implies that family members and other caregivers have a more significant part in the care of those who have a mental illness (Addo et al., 2013). Several studies have demonstrated the benefits of non-institutionalized mental health treatment (Vaingankar et al., 2016); however, there is also evidence of a significant strain placed on caretakers (Addo et al., 2013). Magliano et al. reported that 80% of caregivers feel burdened in their job (2005). Several patient, caregiver, and illness-related factors influence the caregiver burden. These factors include the traits of the patient with a mental disorder, the traits of the caregivers and their relationship, the amount of time the caregiver spends with the patient, and the type and severity of the condition (Kate et al., 2013).

Our findings showed that the overwhelming majority of the carers in families with chronically ill mental patients were women (73%), which aligns with the reports of the World Federation of Mental Health (Copeland, 2010) that across the globe, 80% of caregivers of people with long-term mental illness are women (mother, wife, sister, daughter, aunt or other). Numerous research looking at gender disparities among family caregivers of individuals with mental illnesses have found that women are more likely than men to spend more time providing care and performing personal care duties (Sharma et al., 2016; Xiong et al., 2020). When growing up, women are typically exposed to social standards and expectations of being a 'decent woman.' Not only do they want to be good caregivers for their ailing parents, but they also want to be good parents themselves by caring for their children due to medical or mental health issues (Schneider-Kamp & Askegaard, 2022). In our study, the majority of caregivers cared for a parent (38%), their child (22%), or a sibling (20%). Most of the participating caregivers (75%) were above the age of 41 years, married, and lived in rural areas (60%, respectively). The chronically mentally ill family members they cared for mainly were men (62%), in the age group 41-63 years old (47%), single (68%), unemployed (92%) and lived in the cities (69%). The majority suffered from psychotic disorders (44%), followed by chronic depression (40%) and schizophrenia (16%), and experienced relapse episodes every 6-12 months (76%).

The results of the survey showed that the impact of mental illness had affected many aspects of family life, as stated by Madianos & Economou (2004).

In answering our first research question regarding the perceived carer's burden on the four factors of the Family Burden Questionnaire, our findings showed that the caregivers considered equally as the highest impact burdens the economic burden (F1) (55,6%) and the perception of aggressive behaviors (F2) (55,6%). A growing number of research findings have highlighted the significant social and financial burden that primary caregivers of people with severe mental illness bear (Ae-Ngibise et al., 2015), which is, according to Platt et al. (1985), an "objective burden." The fact that 92% of the participating patients were unemployed may mean that another family member might need to work more to cover the expenses, and the caregiver has to discontinue her employment to care full-time for the mentally challenged relative, imposing, in many cases, a critical financial burden on the whole family. Both medical and non-medical expenses resulting from an illness are considered direct expenditures. Medical costs pertain to the expenses incurred for diagnosis, treatment, and rehabilitation; on the other hand, non-medical costs are associated with the non-healthcare resources used throughout seeking care, such as housing, food, transportation, and household expenses (Jo. 2015). Studies in Canada align with our findings, namely that the unemployment rate among people affected by severe mental illness reaches 70-90%. According to Lipski et al. (2006), family caregivers of people with mental illness frequently face financial difficulties. In similar studies, family caregivers cited financial limitations as the reason they could not provide the appropriate care; such a financial constraint might have a detrimental impact on the treatment of people with mental illness (Savage & Bailey, 2004).

Regarding the perception of aggression, which, according to the participants, ranked as high as the financial burden (55,6%), the caregivers in our study perceived a general upset within the family due to the patient's behaviors in or outside the home. In contrast, Cornaggia et al. (2011) believe that the terms "aggression" and "violence" have been used interchangeably in the relevant literature. It is well documented that one of the main factors influencing caregiver burden in cases of severe mental illness is aggression, especially in schizophrenia and mood disorders (Madathumkovilakath et al., 2018). According to a qualitative study conducted in India, individuals exhibiting positive symptoms of schizophrenia, such as aggressive acting out in public, were associated with negative sentiments of humiliation and unfavorable reactions towards their caregivers (Vargesse et al., 2017). Mental illness's behavioral symptoms have a significant role in the stigma associated with caregivers. The results of an investigation in Egypt showed a correlation between patients' violent conduct and caregivers' perceptions of affiliation stigma (Ebrahim et al., 2020).

As for the third factor in the Family Burden Questionnaire, namely the impact on the caregivers' daily life and social activities, findings in the current study showed that 42% of the family members caring for a chronically ill person felt a high impact

on their daily activities around the house and a significant reduction in their leisure time and socializing. Because their social and recreational activities are restricted and because mental diseases are stigmatized and subject to social prejudice, caregivers often feel alone in society (Chadda, 2014). According to a qualitative study conducted in India, individuals exhibiting positive symptoms of schizophrenia, such as violent or uncontrollably acting out in public, were associated with abuse, which would worsen their condition. Studies in Nordic countries revealed that friends and other family members are crucial support mediators for informal caregivers. They can offer emotional support to the primary caregiver and reduce the intensity of care by splitting up responsibilities and helping the caregiver get assistance (Verbakel et al., 2018).

The last factor relates to caregivers' assessment of the impact on health and behavior in the family when the patient remains at home, cared for by a family member. In this study's sample, only 22% of the caregivers stated that they had severe adverse effects on health and behavior. In contrast, the other 78% experienced low to moderate negative impact on anxiety, nervousness and worry, sleep disturbances, general fatigue, and symptoms of depression. Chadda (2014) poses that because mental illness is often a chronic and demanding condition, caregivers for chronically mentally challenged persons experience stress, anxiety, and depression, which, over time, could lead to burnout and emotional fatigue. Pratima and Jena (2011) claim that caring for an individual with mental illness is linked to increased stress compared to caring for someone with functional impairment arising from other chronic medical conditions. Providing care for a family member with a mental health issue is a dynamic process; the person receiving care changes as their illness develops. In cases where the mental illness of the care receiver is associated with behavioral issues or a physical impairment, the caregiver's job may become more demanding and challenging (Shah et al., 2010).

Moreover, caregivers juggle numerous other responsibilities, such as childrearing, careers, and relationships, making caregiving an even more significant challenge. They are, therefore, more vulnerable to burden, stress, depressive symptoms, and other health issues (<u>Cassie & Sanders, 2008</u>). Researchers have discovered evidence of poor health behaviors, such as skipping their doctor's appointments and eating poorly, among caregivers who help with basic daily living activities like eating and using the restroom, even though relatively few studies have examined this relationship (Burton et al., 2003).

In answering our *second research question*, namely, in detecting how caregivers' demographic characteristics impact the degree of burden they experience, our data showed that male caregivers reported that the chronically mentally ill they cared for exhibited more aggressive behavior than the female caregivers reported. Sharma et al. (2016) posit that in linear regressions, the caregiver's male gender correlated with a higher impression of load. Systematic reviews revealed that gender disparities in care provided by family caregivers of people with mental illnesses are perplexing and inconsistent. The variation in the caring burden is primarily not explained by the caregiver's gender. Adelman et al. (2014) determined that risk factors for caregiver burden include social isolation, low educational attainment, depression symptoms, female gender, financial stress, and poor health.

Another factor influencing the amount of load caregivers carry is their educational background; in the current study, caregivers who were illiterate or only read and wrote had a considerably higher burden than caregivers who had secondary and tertiary education. Nevertheless, the same study determined that higher-educated caregivers experienced more mental strain due to their increased fear of losing their autonomy, which rises with educational attainment.

Last but not least, age impacts the perception of caregiver burden, especially regarding the economic burden and the burden on health and behavior. Our participating older caregivers felt to a greater extent than the younger ones that taking care of a chronically mentally ill family member constituted a burden, primarily an economic burden. Hadrys et al. (2011) showed that when the caregiver was middle-aged or older, patience and emotional resilience were reduced compared to younger caregivers. They also showed that an older caregiver tended to spend more time with the patient than younger carers, who were more likely to split their time between work and other obligations (ibid.). However, in our study, younger caregivers acknowledged that their health and behavior suffered more negative impacts than older caregivers. Similarly, a study of sixty people living with patients diagnosed with schizophrenia found that younger people experienced more anger and depressive symptoms than older people (Zausziewski & Bekhet, 2014). Findings resulting from a relatively recent study in China (Fu et al., 2021) indicated that younger informal caregivers (65 and below years) had significantly higher scores on the Zarit Caregiver Burden Interview (ZBI scores) than their older participants, thus showing clearly a higher perceived amount of burden.

#### 5. CONCLUSION

Researchers worldwide have documented the burden of caring for others as a global issue in Europe, Africa, America, the Middle East, and Asia. Mental illness is often a chronic and demanding condition; therefore, caregivers for patients with mental illness experience stress, anxiety, and depression, which, over time, may lead to burnout and emotional tiredness. Because their social and recreational activities are restricted and because mental diseases are stigmatized and subject to social prejudice, caregivers often feel alone in society. In our study, the majority of caregivers of chronically mentally ill family members experienced a high level of disruption in their family and social life and high levels of health issues manifesting in anxiety and stress, mainly due to these obligations. Caregivers also felt highly exposed to aggressive behaviors and a high level of economic burden, impacting their general quality of life. Indeed, being a caregiver can challenge personal concerns of obligation, accountability, sufficiency, and guilt. Caring long-term for a family member with a chronic mental issue is a dynamic process, as the person receiving care changes

as their illness does. The rehabilitation and welfare of people with mental illness are dependent on the well-being of the caregivers. Hence, maximizing support and counseling services while accounting for the socioeconomic level is essential to ensure caregivers receive solutions specific to their needs. Family caregivers play a very significant role for their loved ones with mental illness, and mental health professionals should respect that role, recognize their efforts, and offer help. We believe that the mental health services of the Ministry of Health should research and register the needs of family caregivers in order to provide more formal and informal opportunities to educate and support family members striving to enhance high-quality health care for their loved ones while at the same time maintaining a high quality of life for their families. Health services should consider revamping the support service model, incorporating the emerging needs for discharge, and offering caregivers the possibility of individual or group counseling and psychoeducation.

#### LIMITATIONS

The study's cross-sectional design prevents a comprehensive understanding of the causal relationship between variables and caregiving outcomes. Moreover, the sample of the participating caregivers was heterogeneous, as women predominated. The literature links factors such as gender to attitudes toward mental illness, which may affect the conclusions drawn based on the mentioned heterogeneity. Finally, the limitations of the electronic survey format were that participants had no opportunity to exchange opinions and answer questions directly. Additionally, the technology required to conduct online surveys may exclude less technologically savvy groups, such as older adults or those with lower education and economic status.

#### FUNDING/FINANCIAL SUPPORT

The authors have no funding to report.

#### ACKNOWLEDGMENT

The authors would like to acknowledge the important contribution of all caregivers to this study.

#### **COMPETING INTERESTS**

The authors have declared that no competing interests exist.

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